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CHAPTER 08



General discussion



8.1 INTRODUCTION

The research question of this thesis was:

“What are possible methods to engage citizens in developing the knowledge base for Health in All Policies (HiAP), and what are challenges and benefits of such engagement?”

As explained in the Introduction to this thesis (Chapter 1), the Whole of Government approach, as a basis for HiAP, needs to be complemented by a Whole of Society approach in which citizens and communities play a major role. We explored ways in which *Citizen Science*, i.e. the active participation of citizens in research, other than as research objects, can contribute to HiAP.

This is the first study, as far as known, in which this approach, as a contribution to HiAP, is addressed. Therefore, an important component of the thesis was the development of a theoretical model to describe, analyse and evaluate Citizen Science in public health (Chapter 2). This theoretical model is based on an exploration of knowledge about Citizen Science in other work fields and insights gained by approaches in public health citizen like participatory action research.

The benefits and challenges in the *practical* application of Citizen Science to support HiAP were explored in three ways. Firstly, by two case studies: one evaluating the impacts of a Citizen Science project in a low-SES neighbourhood in the Netherlands on the citizen scientists (Chapter 3) and one on stakeholder engagement in Health Impact scoping (Chapter 5). Secondly, by carrying out two scoping reviews. The first scoping review concerned community participation in Health Impact Assessment (HIA) because HIA is a key tool for HiAP (Chapter 4). Its results provide insights derived from scientific and grey literature. The second scoping review concerned neighbourhood auditing (Chapter 6). A neighbourhood audit is a systematic assessment of the state of a neighbourhood and those aspects that are important to the health of residents. Thus, it provides evidence that can be used to support local HiAP. In the scoping review, the availability of neighbourhood audit instruments that include residents was explored by looking into scientific and grey literature.

The third way to explore benefits and challenges was by exploring the perceptions, of local professionals, of neighbourhood health assets (Chapter 7). A study, in which local health and welfare professionals were interviewed, was conducted in the same neighbourhood as the Citizen Science project reported on in Chapter 3.

In subsection 8.2, the results of the case studies and scoping reviews will be discussed in relation to the research question. In subsection 8.3 the strengths and limitations of this thesis are discussed. Subsection 8.4 contains concluding remarks and explores possible ways forward in the application of citizen engagement in developing the knowledge base for HiAP.

8.2 SUMMARY AND REFLECTION ON OUTCOMES OF CASE STUDIES AND SCOPING REVIEWS

Citizen engagement in knowledge development for HiAP, or Citizen Science for HiAP, can have different forms. In this thesis, we have focused on three important generic ways to implement a Citizen Science approach. The first one is carrying out a Citizen Science project with lay researchers in their own neighbourhood, as described in Chapter 3. The second, very specific form of Citizen Science is the engagement of communities in Health Impact Assessment (Chapter 4 and 5). The third way to implement a Citizen Science approach is citizen engagement in neighbourhood auditing (Chapter 6). Table 1 provides a summary of the outcomes of the theoretical exploration (Chapter 2), the different case studies and scoping reviews and their results in relation to the research question.

Table 1. Summary of methods, benefits and challenges per chapter

Chapter	Citizen Science methods	Benefits	Challenges
2. Citizen Science for Public Health	<ul style="list-style-type: none"> • Typology of Citizen Science projects, based on aim, approach in the way citizens are engaged (ranging from being data collectors to being in full control of the project) and size (local or mass) 	<ul style="list-style-type: none"> • Increased health literacy • Empowerment • Community building, social capital, social learning and trust • Changes in attitudes, norms and values • Increased Sense of Coherence • Increased participation in public health governance • Lay, local and traditional knowledge added to scientific knowledge • Increased research capacity 	<ul style="list-style-type: none"> • How to engage citizens? • How to address representativeness? • How to weigh scientific and societal value of the knowledge produced? • How to ensure that the participation leads to stronger engagement of citizens in the policy process? • How can this approach lead to better health?
3. Public health Citizen Science; perceived impacts on citizen Scientists. A case study in a low income neighbourhood in the Netherlands	<ul style="list-style-type: none"> • Recruitment by trusted community work centre and mouth-to-mouth • Group meetings • Training (in group) focused on knowledge and personal competences • Trained citizen scientists perform interviews • Support during interview stage (personal, by guideline and by easy to fill out form) • Support for self-organised resident initiatives 	<ul style="list-style-type: none"> • Citizen scientists have better understanding of health and broader health determinants • Citizen scientists have increased knowledge about health and healthy lifestyles • Citizen scientists took action for a healthier life • Self-confidence and social skills of citizen scientists enhanced • Social networks of citizen scientists expanded across cultural boundaries • Citizen scientists took action for a healthier neighbourhood • Increased (measured) health literacy • A set of insights on neighbourhood health assets and barriers 	<ul style="list-style-type: none"> • Lack of (expected) follow-up, causing a sense of powerlessness • Practical organization needs improvement

Table 1. (continued)

Chapter	Citizen Science methods	Benefits	Challenges
4. Community participation in Health Impact Assessment. A scoping review of the literature	<ul style="list-style-type: none"> Community participation as a core element in HIA Knowledge or opinion elicitation methods, in particular, focus groups, interviews, community meetings and workshops Procedures and structures to promote and secure the community's influence in the HIA, in particular Steering Group participation Capacity building, in particular training Multi-method approaches and large variety of methods 	<ul style="list-style-type: none"> Access to lay or local knowledge, improving understanding of local context and improving knowledge base for policy/decision making Adherence to or application of democratic values Improved relations between communities and local agencies Community empowerment 	<ul style="list-style-type: none"> How to select participants and avoid tokenism Cases provide little detail about who are participating and how selection/recruitment took place Cases provide little detail about the methods applied and little information on theoretical or practical considerations underpinning method selection Communities may lack knowledge and capabilities for meaningful participation How to evaluate impacts like empowerment and policy engagement How to embed HIA in broader health promotion strategies
5. We are all experts! Does stakeholder engagement in Health Impact Scoping lead to consensus? A Dutch case study	<ul style="list-style-type: none"> Two subsequent workshops in which stakeholders and residents jointly 1) define joint vision on healthy living environment and 2) apply the vision to infrastructural plan Selection based on ensuring variety of roles of participants; personal invitation Lectures introducing health (determinants) concepts and model of healthy living environment Small group work Group discussion Chatham House Rule 'Everybody is an expert' rule 	<ul style="list-style-type: none"> Joint (experiential) learning Better include community needs in policy development, complementing environmental aspects as defined in regulatory Environmental Impact Assessment framework Health, as a topic, has the potential to connect different stakeholders Enables local stakeholders, including residents, to strengthen their engagement in the policy process Policy adapted to better address community needs 	<ul style="list-style-type: none"> Difficulties in timing and effectiveness of engaging residents and other stakeholders False suggestion of consensus can lead to disappointment and conflict later in policy process

Table 1. (continued)

Chapter	Citizen Science methods	Benefits	Challenges
6. Resident participation in neighbourhood audit tools - a scoping review	<ul style="list-style-type: none">• Resident participation in neighbourhood auditing is not common• Residents participate mostly in data collection; 2 (out of 13) instruments include residents in all project stages, e.g. define aspects to be audited, collect data, help analyse results)• Tools used: Pencil-and-paper checklists, tablet-based tool to record narratives and photos, digital checklist• Exact application of tools not described	<ul style="list-style-type: none">• To gather information on how the local residents perceive their community and the opportunities and barriers for health within their community	<ul style="list-style-type: none">• New technologies are still in development stage, how to ensure that these are resident-friendly?• How to balance, on one hand, relevance for residents and, on the other hand, scientific robustness
7. Neighbourhood health assets: perceptions of local professionals in a Dutch low-SES neighbourhood. A qualitative study	<p><i>Methods to improve resident health (not necessarily Citizen Science methods)</i></p> <ul style="list-style-type: none">• Collective health promotion• Organising or stimulating collective and self-organisation approaches in the community	<p><i>Benefits of collective approaches (not necessarily Citizen Science methods)</i></p> <ul style="list-style-type: none">• Improved social cohesion• Health	<ul style="list-style-type: none">• Challenges for resident health improvement (not necessarily Citizen Science methods)• Poor education• Poverty and unemployment• Lack of social cohesion (including cultural differences)

8.2.1 Methods for citizen engagement in knowledge development for HiAP

This section discusses the most important findings of the case studies and scoping reviews regarding the methods for citizen engagement. Citizen engagement in knowledge production for HiAP is still new, as explained in Chapter 2. Therefore, standard methodologies on how to ensure and manage citizen participation in these Citizen Science approaches are not readily available. Moreover, there is a large variety in Citizen Science applications. Chapter 2 presented a classification based on Citizen Science approach, aim of citizen participation and level of participation. These aspects influence the methods applied. Moreover, the way communities and citizens are involved in knowledge development may vary according to the topic. In Chapter 2, differences between Citizen Science in the natural sciences and public health were discussed. Such differences have an impact on the way projects are conducted. A study concerning bees and their behaviour, for example, may necessitate other methods for citizen engagement than one looking at the opinions of patients about hospital care quality. Citizen Science for HiAP, therefore, possibly requires specific methods and procedures fit for this work field.

Box 1. Classification of case studies in Slottermeer and Vught (Chapter 3 and 5)

Slottermeer (Chapter 3)	
Aim:	Collective goods. Researchers and residents cooperated to create knowledge that may serve as input to improve the neighbourhood’s health
Approach:	Participatory science. Residents participated in problem definition, data collection, and interpretation of data
Level:	Local
Vught (Chapter 5)	
Aim:	Action. Residents and other stakeholders participated to address local concern about the possible impact of infrastructural plan
Approach:	Distributed intelligence. Residents and other stakeholders as interpreters.
Level:	Local

Overlooking the citizen engagement case studies (Chapter 3 and 5, Box 1) , the study under Slottermeer professionals (Chapter 7) and the scoping reviews (Chapter 4 and 6) carried out for this thesis, two key issues come forward, relating to methodological aspects in Citizen Science for HiAP. Firstly, it becomes clear that learning is an important

ingredient of HiAP Citizen Science. Secondly, the creation of social networks appears to be closely linked to Citizen Science approaches.

Learning

Increased skills and knowledge and increased 'scientific literacy' is one of the impacts, and often an explicit aim of Citizen Science in general. Chapter 2 describes that many Citizen Science projects include educational activities aimed at learning. Learning was an essential ingredient in the case study on citizen scientists in Amsterdam (Chapter 3) as well as in the case in Vught (Chapter 5). An important aspect in the Amsterdam case was training of the citizen scientists. This training contained knowledge about health and its social determinants. The influence of the social and physical living environment on health was explained using a translated version of the Egan model (1). This knowledge transfer was combined with strengthening personal competences relevant for the citizen scientists' research activities, for example, supporting them in their attempts to engage fellow-residents for interviews. In the Vught case, there was a focus on joint learning of all participants: residents as well as other stakeholders were involved. Here, again, core issues were concepts of health and those factors that affect people's health and health behaviour, using the Egan model to refer to the living environment.

In HIA in general, learning is an important aspect of the participation of communities. The scoping review on community participation in Health Impact Assessment (Chapter 4) revealed that one of the methods applied to enable such participation was training of community members. The details of such training were not described. However, what is clear, is that, similar to the case studies in this thesis, in HIA in general, learning is linked to concrete issues that are relevant to the participants on a personal level, as this always takes place in the framework of a specific local context and in relation to concrete policy proposals. Examples of training include topics like water or waste, but also generic understanding of health and its determinants.

This approach, where learning is stimulated by the confrontation between the knowledge transferred, including abstract concepts or models, and the concrete experiences of the participants, can be considered 'experiential learning', a term coined by Kolb (2). As Kolb explains, bringing knowledge and experience together in this way provides meaning and vividness to the –new, experiential- knowledge thus produced by the participants. In experiential learning, the process is more important than fixed outcomes and the learning is action-oriented, aiming at the application of knowledge in the participants' own context.

Experiential learning, where knowledge and action are so closely related, is highly relevant for Citizen Science for HiAP, because HiAP is by definition an action-focused approach, aiming to resolve important ‘wicked’ health challenges. The same, can be argued, is true for health promotion research in general (3).

Learning is not only an important element for the citizens contributing to knowledge development; cocreation in knowledge development entails mutual learning for both the community and researchers (4). For HiAP, other stakeholders, in particular local professionals, may need to be engaged in this joint learning process as well. Local professionals in Sloterveer (Chapter 7) have little confidence in the knowledge and capabilities of local residents to identify and utilize neighbourhood health assets. Their approach to improving the health of residents is mainly deficit-based. The scoping review concerning citizen participation in neighbourhood audit tools reveals a similar, expert-based approach in which residents’ knowledge has no place. Developing asset-based approaches in public health, however, does not happen by itself; it requires a change of both professional and organizational cultures and values. A shift towards the application of asset-based approaches can be promoted by developing the public health work force through formal training, empowering them to explore and experiment new ways to operate with their target groups (5, 6). Learning processes of professionals and communities or citizens need not take place in separate ‘streams’; indeed, dialogue with target groups may be a useful way to develop new knowledge, competences and attitudes. In the Vught case (Chapter 5), both residents and professionals developed a broader and more holistic perception of health. The learning process happened by confronting different points of view, listening to one another and reflecting on differences and commonalities. In HIA in general, the input of communities is perceived as a way to access knowledge that would otherwise not be available to the professionals engaged in the Impact Assessment – thus as a way of learning more about those communities (Chapter 4).

Social networks

Citizen Science brings people together in networks or communities of ‘lay researchers’ that help the participants to develop new (scientific and other) competences and knowledge (Chapter 2). Wallerstein (7) argues that joint critical thinking about the local context helps build community capacity and empower individuals within that community. This was also an important aspect in the case studies in Amsterdam and Vught (Chapters 3 and 5). The element of group-based learning was at the core of the approaches applied in these cases. The citizen scientists in Amsterdam, like the participants in the scoping workshops in Vught, developed their views and knowledge by sharing and discussing them in the group. There was also space to discuss different

points of view. The citizen scientists in Amsterdam emphasized that they learnt to respect, acknowledge and understand people with another cultural background. In the Vught evaluation, it became clear that mutual respect and trust were supported by the two ground rules of the workshops. These rules were the Chatham House Rule (8) and the 'Everybody is an Expert' rule, the latter designed by the workshop developers. In HIA, group based approaches are important methods to engage communities and access local knowledge. Moreover, inclusion of community members in a HIA Steering group is frequently mentioned in the literature studied (Chapter 4).

This group-based aspect of Citizen Science links up to the theory and practice of health promotion. Strengthening community action is one of the four Ottawa Charter key areas (9). Community-based approaches are important in health promotion; these approaches are applied widely in a multitude of health promotion strategies and interventions worldwide. An important element is the empowerment of communities or community groups, strengthening them to take joint action for their community's health. It is this notion that one might recognize in the statements made by the professionals in Amsterdam, interviewed about health and health assets in the neighbourhood (Chapter 7). The focus on individual self-sufficiency in current Dutch health and wellbeing policies, linked to the concept of 'positive health' as the ability to adapt and self-manage (10), does not seem to resound in the way these professionals perceive the local situation. Instead, they advocated developing or applying approaches where the focus would be on group (or community) empowerment rather than on individual empowerment. They mentioned examples like health promotion in peer groups or self-organisation of residents as possible ways forward. Although, in the perception of these professionals, residents, on an individual level, underutilised important neighbourhood assets, community-based assets approaches seem to hold a promise for the improvement of the neighbourhood's health. This would require developing a collective conceptualisation of 'positive health' as an enrichment of the current focus on individual capacities. Moreover, it would require to link this 'positive community health' to environmental factors and living circumstances that pose opportunities -and barriers- to community health. Such approaches could include the joint development of views and knowledge with residents.

On a more generic level, the group-based character of Citizen Science approaches can be considered as particularly meaningful in the framework of HiAP. The Whole of Society approach, which is essential for effective HiAP, by definition requires cooperation of different societal actors, including citizens, to address joint health challenges. The groups and networks built up through Citizen Science projects may provide a mechanism that enables residents to act as partners in such cooperation.

8.2.2 Benefits of citizen engagement in developing a HiAP knowledge base

In Chapter 2, a model of possible benefits of Citizen Science was presented. The benefits may be divided in two categories, namely benefits for knowledge development and benefits for citizen scientists. Both types of benefits were addressed in the case studies and scoping reviews underlying this thesis.

Benefits for knowledge development

In Citizen Science literature, the expansion of (quantitative) research capacity is often mentioned as the main benefit for knowledge development (Chapter 2). However, this may be only partly true for Citizen Science in the framework of HiAP which takes place in a complex social context. In that context, all kinds of practical, ethical, political or social issues may arise, requiring thoughtful planning and management throughout the project. The Sloterveer case (Chapter 3) illustrates this. Although the citizen scientists managed to reach out to a large group of residents, enhancing data collection capacity, considerable effort was invested in training and ongoing support of the citizen scientists. In sum therefore, working with citizen scientists - in this case- probably did not reduce time investment. The enhancement of 'qualitative' research capacity was more important: the citizen scientists functioned as trusted key persons without whom it would have been difficult to establish contact and perform interviews with this local population.

This thesis shows that Citizen Science for HiAP, in addition to –possibly- increasing research capacity, benefits knowledge development in three other, qualitative, ways. Firstly, Citizen Science yields contextual information that is useful as a background against which HiAP strategies can be developed. Secondly, Citizen Science helps balance one-sided information by providing insider knowledge. Thirdly, Citizen Science has the potential to yield socially robust knowledge, i.e. knowledge that is contextualised and that is developed in an iterative process between scientists, society and citizens (11). The case studies and scoping reviews in this thesis illustrate how types of benefits could materialise in practice.

The first type of knowledge benefits is discussed in the scoping review on Community participation in HIA (Chapter 4). This scoping review showed that the contribution of communities and citizens to the knowledge needed for HiAP is a key consideration underpinning community participation in HIA. The input of communities in the HIA process provides knowledge that helps to understand the local context. This, subsequently, enables the development of appropriate and effective policy options

that link up with that local context. Indeed, ideally, an effective HIA should lead to adaptations of proposed policies, plans or programs in order to protect or improve the health of a population or population group (12).

The second type of knowledge benefits can be observed in the case study in Vught (Chapter 5), where resident knowledge provided new insights that were pertinent to the local situation. One of the insights was that noise or noise reduction was not the only issue at stake, but that connectivity within the community was at least as important. This could only be known by engaging and listening to residents, who held important information on, for example, the needs of people with visual impairments living in Vught.

Such knowledge and insights need, of course, not always be collected by a Citizen Science approach. Other strategies, like interviewing residents, pose alternatives. The added value of Citizen Science is the creation of the third type of knowledge benefits, socially robust knowledge. This is created by combining lay and expert ways of understanding reality and initiating dialogues in which they are compared, confronted and integrated. Balancing different views, perceptions and ways of knowing might sometimes require a 'partisan' position where researchers explicitly and intentionally side up with underprivileged groups, strengthening voices that are seldom heard (13). The result, socially robust, shared knowledge, including such currently underutilised 'lay' knowledge, can underpin ways forward to address wicked (health) problems (11, 14). However, the extent to which such knowledge is created might depend, at least partly, on the type of Citizen Science approach applied. Table 2 shows the potential knowledge benefits of different Citizen Science approaches, assuming that the extent to which citizens or communities play an active part in a project has an impact on these potential benefits.

The role of Citizen Science in attaining socially robust knowledge is illustrated by the cases in this thesis. In Vught, it was the development of a joint vision, with residents and other stakeholders, on a healthy living environment, and the application of that vision on an infrastructural plan, that created the basis for adaptation of the infrastructural plan. In Amsterdam, the local professionals had the impression that residents (Chapter 7) underutilized available local health assets. Studying the neighbourhood with residents provided the 'insider's view' of residents regarding these assets but also enhanced the citizen scientists' abilities to interact with their environment: a first step towards socially robust knowledge and, at the same time, towards improvement of the situation observed by the professionals.

Table 2. Citizen Science approaches and potential knowledge benefits

Approaches	Potential knowledge benefits		
	Insiders' knowledge	Contextual knowledge	Socially robust knowledge
E. Extreme Citizen Science. Citizens in charge from problem definition, data collection and analysis, to interpretation and knowledge development	++	++	++
F. Participatory science: Participation of citizens in problem definition and data collection	++	++	++
G. Distributed intelligence c) Citizens as basic interpreters d) Volunteered thinking	+-	+-	--
H. Crowd sourcing c) Citizens as sensors d) Volunteered computing	+-	--	--

Improving the knowledge base for HiAP by applying Citizen Science is a new -and promising- perspective, rather than regular practice. Much still needs to be developed, experimented, and evaluated. An example of a work field where Citizen Science may develop is neighbourhood auditing. The scoping review on instruments currently applied in this work field (Chapter 6) showed that, in these instruments, the focus is on expert views, rather than on the lived experience of residents. The ‘objectiveness’ of expert evaluation of a neighbourhood seems to be core and there is a strong focus on inter-rater reliability. For these audits to yield socially robust knowledge, residents would need to be engaged, not merely as informants, but as partners in the auditing process. The scoping review showed that first steps are taken to design more participative auditing instruments and procedures aiming at production of enriched, socially robust, knowledge.

Potential benefits for citizen scientists

As explained in Chapter 2, public health Citizen Science may contribute to health promotion goals. The benefits for citizen scientists, as included in the model developed, are increased health literacy, empowerment, community building, social capital, social learning, trust, and changes in attitudes, norms and values. More indirectly, the model (Figure 1) shows that impacts can be expected on the citizen scientists’ Sense of Coherence (SOC) and participation in public health governance.



Figure 1. Effects of Citizen Science on health, health governance and knowledge system

The case studies about citizen scientists in Amsterdam (Chapter 3) and about Health Impact Scoping in Vught (Chapter 5) illustrate how these benefits may materialize. In both cases, the participants reported to have enhanced their knowledge about health and the impact, on health, of the living environment. In Amsterdam, health literacy was increased. In Vught, there was an impact on mutual understanding, based on respect and trust between residents and other stakeholders. In Amsterdam, the citizen scientists extended their social networks beyond their own cultural group. In both cases, the participants felt empowered by the process, being listened to, having learnt new skills, and being placed in a new position as ‘experiential experts’. Attitudes, in particular attitudes regarding other people, like other cultural groups (Amsterdam) or national and local stakeholders (Vught) changed: working and communicating with one another, as well as joint learning helped to create a sense of deepened understanding. The topic health was, in both cases, experienced as an issue that helps connect people with different (cultural or professional) backgrounds.

Not all benefits were measured or otherwise assessed in both studies (Table 3). Moreover, as explained in Chapter 3, in reality, different impacts are intertwined with one another and hard to separate as depicted in the model. However, the model proved to be a good framework as a starting point for analysis, as it helps identify impacts while also showing how these are linked to one another.

The scoping review on community participation in HIA (Chapter 4) revealed that similar impacts are expected on the communities engaged in HIA, in particular empowerment. However, it is also clear that exactly these impacts are not well documented as yet.

Table 3. Impacts measured in case studies in Vught (A) and Sloterveer (B)

Benefit	8. Active participation in health governance	9. Sense of Coherence	4. Health literacy	5. Empowerment	6. Community building, social capital, social learning, trust	7. Changes in attitudes, norms, values
Measured	-	B	B	-	-	-
Otherwise assessed	B	-	-	B, A	B, A	B,A
Not assessed	A	A	A	-	-	-

The impacts on SOC were evaluated in the case study in Amsterdam by measuring SOC before and after using the SOC-13 scale; no significant change in SOC could be detected. There are indications that health promotion interventions do have the potential to strengthen SOC, by helping the target group to identify everyday life stressors and the resources that could help address these stressors (15). For Citizen Science approaches to have this impact, therefore, they would need to be directed differently and it is questionable whether this is a requirement that can be met in the framework of HiAP focused Citizen Science work. However, they could identify stressors and resources on a community level that may then be addressed by other intervention strategies.

It is unclear to what extent active participation in governance was stimulated – this was not looked into in the studies in Vught and Amsterdam. It must be noted however, that in both cases, the citizens participating expressed doubt about future policy development and what influence they would be able to exert on these policies. The scoping review on community participation in HIA showed that it is common, in the field of HIA, to expect that participation stimulates policy engagement in the longer run. However, this still needs to be demonstrated in practice – evaluation on this issue is still lacking. One important condition may be sustained engagement in the Citizen Science process and embedment in broader HiAP strategies. Community health promotion requires a long-term approach as activating and sustaining community groups takes time (16). The same may be true for Citizen Science as a practice promoting both health and engagement in health governance.

8.2.3 Challenges for citizen engagement in developing a HiAP knowledge base

The studies in this thesis showed that Citizen Science for HiAP, as a novel practice, deserves further development. Two challenges need to be addressed regarding the participation of communities: firstly, which community members to engage and, secondly, how to engage these community members. A third, more fundamental, challenge relates to the scientific and societal quality of the research.

The first challenge refers to the selection of citizen scientists: finding and inviting the right people. Different groups may also have different interests, knowledge and capabilities. The Vught case (Chapter 5) showed that residents engaged felt that a broader group should have been invited. The chapter on the scoping review about community participation in HIA (Chapter 4) showed that several authors were concerned that selected participants might not represent the community or that they would be unfit to meaningfully participate. They stated that this might lead to tokenism or to making communities responsible for decisions that harm their wellbeing. The professionals interviewed in the underprivileged Sloterveer neighbourhood in Amsterdam (Chapter 7) expressed a similar concern about the abilities of the local community to identify and use neighbourhood assets. However, Chapter 3 shows an example of an effective Citizen Science project in that same neighbourhood where residents, as citizen scientists, provided valuable input. When starting a Citizen Science project it is necessary to be precise in defining what exact groups will be engaged, because different groups may have different interests, insights and needs. In any given case of citizen engagement in knowledge development for HiAP it will be necessary to consider whether participants have a specific mandate to speak on behalf of their community or specific community groups, and how to guarantee that all voices are heard. Health promotion focusing on addressing community needs, in general, has to deal with such (ethical as well as practical) questions (17), and Citizen Science approaches for HiAP are no exception here.

Secondly, when it is clear who should participate, challenges arise in engaging these persons or groups and securing their participation in the longer run. Specific expertise in reaching out to underprivileged or marginalized groups and engaging them is essential. This may necessitate cooperation with local community development work and community health work as performed in the case in Sloterveer (Chapter 3). One promising way is also to engage (trained) community key persons (18). However, more is needed if Citizen Science is to support HiAP. Participation should entail more than merely collecting data, for example discussing research questions and analysis. There needs to be an ongoing dialogue about shared –or disputed– knowledge between researchers and citizen scientists. The results of the research should be shared and an

action perspective should be included (19). Here, once again, it is possible to build on the wealth of experience and knowledge available in health promotion, in particular in Participatory Action Research (PAR) (20), as this approach inherently combines research with a focus on action for health improvement.

On a more fundamental level, questions might be raised about the quality of the research carried out with communities or citizens (21). There are different strategies that may offer solutions to ensure scientific quality. First of all, to be clear about the goals of the research. It makes a difference if it is aimed, for example, at collecting and comparing (epidemiological) data or at deepening insight into the experiences of local people. The typology of Citizen Science (Chapter 2) shows different Citizen Science aims and approaches. Secondly, the methods should be clear, including the role of the citizen scientists. Basically, this is not different from any other quality requirements for research. The scoping review on HIA (Chapter 4) showed that the methods applied in this field seem to lack theoretical and empirical underpinning.

As Citizen Science for HiAP has a societal goal, namely to inform HiAP strategies including a variety of societal stakeholders, research quality does not only mean scientific value, but also societal value. This means that this research should have value for the communities participating, but also for a broader group of stakeholders that are engaged in Whole of Society approaches to address (wicked) health challenges. Once again, this requirement does not only refer to Citizen Science projects, but to other research as well (22). The challenge, however, would be to develop evaluation tools or methods that are fit for Citizen Science projects in relation to HiAP. Current evaluation tools, for example as developed by the Evaluating Research in Context (ERiC) partnership in the Netherlands (23) are rather generic and do not explicitly include community benefits. Moreover, in public health currently the results of collective approaches are often measured at the individual level. Herens (24) provides an example of multilevel evaluation of community interventions that may be helpful, assessing results on the individual, group, community and program level. Similar evaluative frameworks could be developed for Citizen Science projects, including the spin-off of the projects in terms of creating community or citizen networks that contribute to Whole of Society strategies to address wicked health problems.

8.3 STRENGTHS AND LIMITATIONS

A strength of the research carried out as the basis for this thesis is the combination of different methods. A theoretical exploration was carried out, as well as qualitative field studies and scoping reviews. Moreover, different qualitative methods were applied. In

one of the case studies, qualitative methods were combined with the application of a questionnaire.

Access to lay knowledge and experience, adding depth and richness to available (epidemiological) knowledge is one of the benefits of Citizen Science. The qualitative perspective applied in this thesis links up with this aspect; therefore it is a suitable approach to explore Citizen Science application for HiAP.

Two of the three case studies in thesis were carried out as Citizen Science projects. The method applied to evaluate these case studies can be categorized as Participatory Action Research. This is, again, an approach that suits the topic. Citizen Science is a joint effort between scientists and lay people; in Citizen Science approaches for HiAP this includes public health (and other) professionals as well. Therefore, not only communities or citizens take on a new role, the same is true for both the researcher and local professionals. In this case, there was a close connection between the researcher, professionals and the group studied: the researcher conducted focus groups and interviews, but was also present at important meetings of the citizen scientists groups. This is a second strength of the research underlying this thesis. Brown (25) describes how, in environmental health research with local communities, the personal commitment of the researcher to the community involved and aspects like empathy and trust are important factors determining the quality of the research. The impact of shifting roles of researchers, professionals and citizen scientists is a topic that was not studied in this thesis. However, it is a topic that deserves attention in further work developing Citizen Science approaches for HiAP.

A limitation of this thesis is that the case studies were small scale, local field studies that did not specifically address all possible benefits and challenges for Citizen Science in the framework of HiAP. To be able to draw more generic conclusions about the impacts of Citizen Science in practice, more extensive research over longer times and in more places is needed. However, Citizen Science is just developing. It seems realistic to expect that this kind of broader evaluation will only be possible in several years.

A second limitation, for the scoping reviews, is the search strategy which was focused on publications in English, therefore possibly missing relevant publications in other languages. As scientific literature is published more and more often in English, it is not very probable that this may have seriously influenced the outcomes of the study; however, additional research in different languages may be useful in future, in particular looking into smaller, locally based projects.

8.4 CITIZEN SCIENCE FOR HIAP – WAYS FORWARD

This thesis has explored Citizen Science approaches as a way to support HiAP. It shows that the Whole of Society approach, needed for effective HiAP (26) may be enriched by including communities and citizens in the knowledge basis underpinning this approach. The socially robust knowledge thus produced can be important input to effectively address health challenges. The thesis showed that a variety of methods may be applied in Citizen Science in the framework of HiAP, but also, that theoretically and practically underpinning the methods still needs attention. The thesis also provides insight in possible benefits for the citizen scientists. Citizen Science in the field of public health links up with asset-based approaches, recognizing and enhancing the abilities and skills of communities and citizens to address health challenges. More fundamentally, Citizen Science, as a participatory research practice, links up with important societal values underpinning health promotion: democracy, transparency in decision-making and equity. Citizen Science may help ensure that the concerns of citizens and communities are heard and legitimized. Labonte (16) argues that truly empowering health promotion, or in his words, ‘transitive’ empowerment, taps into the complexity of daily life experiences of citizens. The Dutch Social and Cultural Report 2014 describes that underprivileged groups with little social, cultural, economic and personal capital experience discomfort with differences in society (27). One aspect of that discomfort is distrust in scientists, whom they perceive as part of a societal elite. As demonstrated in this thesis, participation in Citizen Science may benefit these groups by increasing their knowledge, social networks and strengthening their influence on local decision-making, in short, it may increase their societal opportunities. Moreover, dialogue between scientists and these groups may, in itself, be useful in the light of creating a better mutual understanding. Whether this will decrease their generic sense of discomfort remains a question. Still, it seems worthwhile to explore the possibilities that Citizen Science has to offer for these groups – preferably in a bottom-up process.

Overlooking the different chapters in this thesis, the conclusion seems justified that Citizen Science has important potential to contribute to HiAP, but that it should not be equalled to ‘cheap data collection’ or ‘easy science’. To realise the promise of Citizen Science for HiAP, work needs to be done to further develop the approach. This requires substantial input in terms of time, attention and possibly budgets. However, it may provide important contributions to the resolution of current wicked health problems. Four strategic directions are important:

- 1) Methodological innovation in research underpinning HiAP is necessary, firstly in terms of improving the balance between qualitative and quantitative methods.

The knowledge base for HiAP, to be supportive for the Whole of Society approach needed to address wicked health problems, needs to provide a multidimensional perspective. Such a perspective connects quantitative and epidemiological knowledge with qualitative knowledge, including lay, local and traditional knowledge of communities and citizens. Secondly, innovation may come across by exploring technological possibilities like ‘quantified self’ approaches and app technology as ways, for citizens, to conduct their own research or to participate in broader research projects.

- 2) Investing in citizen scientists is a necessary requirement to ensure that the approach yields the benefits described in this thesis. In particular, (experiential) learning is a key element in Citizen Science for HiAP, especially where underprivileged groups are concerned. Methods to enhance abilities of communities and citizens to act as co-researchers need to be further developed and tested in practice. Investing in citizen scientists does not only yield better or more (contextual) knowledge; it may also aim at creating community capacity, knowledge and skills as well as community networks that support community engagement in local HiAP processes.
- 3) Connecting Citizen Science approaches with broader HiAP strategies is needed if the knowledge developed with and by communities and citizens should contribute to these strategies. Reversely, HiAP strategies should rely on a knowledge base built by applying different methodologies, including Citizen Science approaches.
- 4) Finally, evaluation of community participation in creating a HiAP knowledge base is needed. In such evaluation, both societal and scientific quality should be addressed. Moreover, it should be multiperspective (community/citizen, policy, professional and other stakeholder perspectives), multidimensional (process, methods and outcomes) and multilevel (individual, group, community and program or policy). Such evaluation requires a mixed method approach (28, 29), perhaps involving the target groups engaged in the projects; community based evaluation may further empower these groups (30). The benefits of Citizen Science model presented in Chapter 2 could serve as a starting point for a framework for evaluation of HiAP Citizen Science approaches.

Box 2 shows a summary of the recommendations for policy, practice and research.

Box 2. Summary of recommendations for policy, practice and research

General recommendation

- Detect gaps in the HiAP knowledge base in cooperation with all stakeholders, including communities, and discuss how these stakeholders could contribute to address these knowledge gaps.

Recommendations for policy

- Broaden up the knowledge basis for decision making with knowledge developed by carrying out Citizen Science projects;
- Stimulate the development of such knowledge, for example by commissioning community based Health Impact Assessment of proposed policies, programmes or projects;
- Stimulate the formation and ongoing support of community groups that could contribute to knowledge development for HiAP.

Recommendations for practice

- Develop asset-based approaches with the target groups using joint knowledge development with these target groups as a strategy;
- Support communities in building skills for knowledge creation.

Recommendations for research

- Carry out experiments with various innovative Citizen Science approaches;
- In research design, planning and budgeting, consider the options for engagement of citizens in the research process;
- Plan ‘valorisation’ of knowledge production with communities: contribution to broader HiAP strategies and continued community engagement after finalization of research projects;
- Develop (participatory) evaluation frameworks and methods for HiAP Citizen Science projects.

8.5 IN CONCLUSION

This thesis has explored the methods, benefits and challenges of applying Citizen Science approaches in developing a HiAP knowledge base. This was the first exploration around this topic, as far as known.

It seems that the application of Citizen Science may contribute to socially robust knowledge to underpin HiAP. It may also help build Whole-of-Society networks of citizens, communities and other stakeholders, that are important for effective HiAP. And, finally, Citizen Science may be applied as a health promotion intervention, empowering and supporting communities to address their health needs.

However, Citizen Science is new for the field of public health, although it has links to and sometimes resemblance with, existing participatory action research approaches. There are challenges regarding the selection of participants and methods applied. Moreover, the scientific and societal value of the results of HiAP Citizen Science projects needs a critical examination. Therefore, the approach needs to be not only further developed, but, more importantly, experimented and evaluated.

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